Author's response to reviews

Title: Missed opportunities for impact in patient and carer involvement: a mixed methods case study of research priority setting

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Author's response to reviews: see over
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Dear Dr Staniszewska and Mr Stephens

Thank you very much for considering our paper for publication in Research Involvement and Engagement, and for your and the reviewers’ helpful comments. We have done our best to address them – please see our responses in bold below and tracked changes in the attached manuscript.

We look forward to hearing from you.

Yours sincerely,

Joanna Crocker (corresponding author)

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Editor’s comments:
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Thank you for submitting this interesting paper in an important area of work. The reviewers were supportive of the paper but had some suggestions for strengthening it which we would like you to address. The Editors would like to also to address the following comments which reflect some of the reviewer comments.

- Please read the paper for sense and flow. On occasion it is difficult to follow. The acronyms make it harder to read in parts so please consider using full descriptions.
  We have removed the acronyms “NATU”, “HCP” and “PSP”. We have also asked a lay contributor to review and revise the paper to improve its accessibility, sense and flow. We describe her contribution and impact under ‘Co-creation of this study’.
- Please include an aim in the abstract to make the intent of the paper clearer.
  We have now included an aim in the abstract.
- The abstract requires clarification as it feels oblique in some places and the key points get a little lost. The main abstract and the plain English one feel different in the focus of findings, so perhaps need greater alignment. The paper has come important messages but they are somewhat hidden at the moment.
  We have substantially revised the abstract and Plain English summary (with input from our lay contributor) for clarification, sense and alignment.
- It would be useful to include an aims sections before the methods (particularly as there are a number of possible aims covered in the paper).
  We have now included a clear aims section in the paper.
- While methods are described elsewhere, please consider whether those methods should be summarised here to provide context for the paper as it should stand alone for the reader. It may be worth splitting the methods into key sections. At the moment it is not clear how many steps the study had.
  We have split the Methods section into sub-sections and provided more detail, including three Additional files (the survey, background information sheet and promotional flyer).
- Please also assure us that this paper provides an additional perspective to the one already published which appears to report the results of the PSP.
  We have clarified in the first paragraph of the Methods section that the paper already published described but did not analyse the PSP process.
- Please add further detail of the online and paper survey as this is the key method underpinning the paper. Thus a description of development, the survey itself, and how it was evaluated or not for robustness.

We have provided further details of the survey in the Methods sub-section entitled ‘Identifying potential research questions’, as well as a copy of the survey itself (Additional file 1).

- Ethical aspects? please move the ethical approval section to before the methods. Please confirm that all activity was covered by ethical approval.

The following statement now appears in the Aims section: “This study was fully approved by the Medical Sciences Interdivisional Research Ethics Committee, University of Oxford.”

- Please state how the sample were identified, contacted and recruited.

This information is now included in the section of the Methods entitled ‘Identifying potential research questions’.

- It may be worth reflecting on the nature of research questions in more depth and the challenges this might pose for conventional forms of evidence.

We have added this to the Conclusion (final paragraph).

- Consider the international implications for such practice. Many other countries are considering how to involve patients in identifying research questions and it would be useful to identify any international implications.

We have highlighted the international relevance of our findings in the Conclusion of the paper, and clarified the international nature of the evidence base with which we compare our findings in the Discussion section.

Although one of the reviewers suggests broadening the paper out, we would encourage you to focus on this as a single case study.

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Referee 1

Minor Essential Revisions

Thank you for your advice regarding the readability of our Plain English summary. With help from our lay contributor, we have revised this summary so that the Gunning Fog index is now 8.18, corresponding to a reading age of 12 years in the UK.

We have removed several of the acronyms as requested, including “NATU”, “HCP” and “PSP”.

Discretionary Revisions

We have revised the abstract and Methods section of the paper to improve their sense and readability.

We have reproduced relevant methods from the original paper (reference 18) in this paper so that there is now a fuller description of what was done.

With regard to the comment about our statistical analysis, we think this is a misunderstanding. We compared percentages within each group of respondents, not absolute numbers, so although the sample sizes are different these groups are statistically comparable.

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Referee 2

Thank you for your supportive comments.

Referee 3

As per the Editors’ advice, we have not tried to include other case studies in this paper.

Participants were not asked what they felt about their research questions being rejected, partly because they were anonymous, so could not be contacted individually. We have added a sentence to the Discussion section to clarify that direct dialogue with participants was not possible due to their anonymity.